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Multidisciplinary care for people with Parkinson's disease: the New Kids on the Block!

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Abstract

Introduction: Parkinson's disease (PD) is a chronic multisystem disorder that causes a wide variety of motor and non-motor symptoms. Over time, the progressive nature of the disease increases the risk of complications such as falls and loss of independence, having a profound impact on quality of life. The complexity and heterogeneity of symptoms therefore warrant a holistic, multidisciplinary approach. Specific healthcare professionals, e.g. the movement disorders neurologist and the PD nurse specialist, are considered essential members of this multidisciplinary team. However, with our increasing knowledge about different aspects of the disease, other disciplines are also being recognized as important contributors to the healthcare team.

Areas covered: We describe a selection of these relatively newly-recognized disciplines, including the specialist in vascular medicine, gastroenterologist, pulmonologist, neuro-ophthalmologist, urologist, geriatrician/elderly care physician, palliative care specialist and the dentist. Furthermore, we share the view of a person with PD on how patients and caregivers should be involved in the multidisciplinary team. Finally, we have included a perspective on the new role of the movement disorder neurologist, with care delivery via "tele-neurology".

Expert commentary: Increased awareness about the potential role of these 'new' professionals will further improve disease management and quality of life of PD patients.

1. Introduction

Parkinson's disease (PD) is a chronic, multisystem neurological disorder with a complex and heterogeneous phenotype [1]. The classic description of PD as a condition that predominantly affects the motor system (e.g. with symptoms such as tremor, rigidity, postural instability and gait impairment) has become largely obsolete, since most patients also experience a wide variety of non-motor symptoms (e.g. psychiatric or sleep disturbances, autonomic or cognitive dysfunction) [2,3]. These non-motor symptoms can have a major impact on quality of life and are an important source of disability, leading to hospitalization and institutionalization [4]. Moreover, dopaminergic treatment may sometimes worsen non-motor symptoms, such as orthostatic hypotension or hallucinations [5]. Currently, PD management with pharmacotherapy or neurosurgery alone is usually effective in reducing the classical motor features, but is insufficient to address the entire spectrum of symptoms. Many patients become progressively disabled as the disease advances, because of serious complications that are largely unresponsive to current pharmacological interventions [6]. Therefore, a multidisciplinary team that assembles healthcare professionals from different disciplines is essential to achieve safe and effective care [7], including the promotion and integration of self-management [8]. Here, it is important to distinguish between multidisciplinary and interdisciplinary care. With multidisciplinary approaches, each individual team member approaches the patient from their own perspective. Usually, this approach involves a series of parallel, separate consultations and the decisions made may or may not be integrated by a team leader. In contrast, interdisciplinary care emerges from multidisciplinary care when healthcare professionals make group decision about patient care, usually facilitated by face-to-face meetings [9,10]. Importantly, in this paper we have chosen to use the term "multidisciplinary" in its broadest sense, because our main aim is to describe specific roles of different healthcare professionals within the team, but not the type of communication between these different healthcare professionals within this team.

In this paper, we explore relatively newly recognized, yet potentially important contributors to the multidisciplinary team of people with PD, with the aim of highlighting the specific roles of these healthcare professionals. Furthermore, we hope to raise further awareness about the range of non-motor symptoms that individuals with PD may experience, often affecting activities of daily living and leading to reduced participation in society [11]. This scoping review will therefore contribute to improved disease management by allowing clinicians to earlier identify non-motor symptoms (many of these are currently missed during routine clinical consultations) and to subsequently draw on the expertise of the specific professionals introduced in this paper. Specifically, we will review the roles of the following disciplines by means of an expert contribution in each specific field: the specialist in vascular medicine, gastroenterologist, pulmonologist, neuro-ophthalmologist, urologist, geriatrician/elderly care physician, palliative care specialist and the dentist. In each section, we will describe the following topics: (1) the role of the professional in the multidisciplinary team; (2) the prevalence and impact of clinical problems for which this professional can offer help; (3) frequently occurring clinical problems; and (4) the available treatment options. Furthermore, we share the view of a person with PD on how patients and their caregivers should be involved in the multidisciplinary team and how this can improve self-management. Finally, we have included the view of the movement disorder neurologist, with a special focus on the increasing potential of "tele-neurology", since care provided via telemedicine is a relatively new way of implementing multidisciplinary care directly into the patient's own home. Indeed, we expect tele-neurology to soon spread well beyond neurological consultations and to also involve a remote multidisciplinary care team (e.g. including the PD nurse or

physiotherapist). *Figure 1* shows an example of the multidisciplinary team of a person with PD, including the traditional care team and the “new kids on the block” described here. Importantly, we would like to emphasize that this overview is based on the combined personal expertise and experiences of the authors and does not aim to be exhaustive. It rather presents a selection of several as yet relatively unknown professionals in the field of PD, all of whom may help to improve the quality of life in this complex patient population.

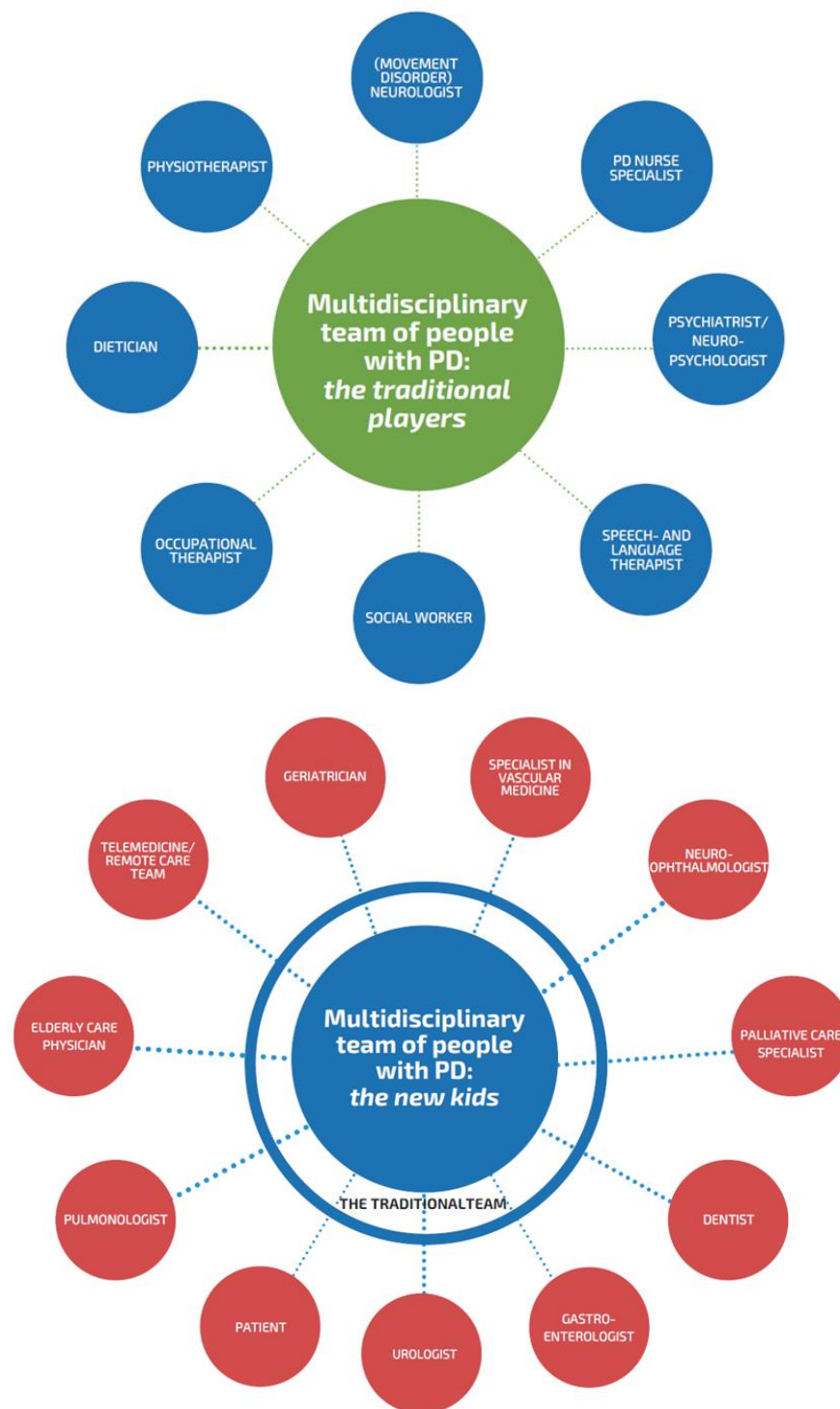


Figure 1. Example of the multidisciplinary team of a person with PD.

2. The new kids on the block

2.1 The person with PD

Multidisciplinary care is of extreme importance for the treatment of people living with PD. The effectiveness of this approach, however, critically relies on the participation of the patient and caregiver(s) in this multidisciplinary team. This patient-as-partner approach is increasingly being adopted in the care for people with chronic diseases [12] and, for example, on the Intensive Care Unit [13]. Using this approach, patients become a true member of the multidisciplinary team endowed with competencies and limitations, just like any other team member, as opposed to a patient-centered approach, where patients are solely at the center of the healthcare professionals' work, but do not participate in the team [12]. Currently, most of the treatment for people with PD focuses on symptomatic relief; and patients are in the best position to tell other team members about the symptoms that have the greatest impact on their personal quality of life. The patient is most often the bridge between two or more healthcare professionals. In addition, the patient can assist the team in asking and answering the right questions. How will the neurologist, for example, be aware that the patient has significant periodontal disease unless the patient shares this information and connects the neurologist with the dentist? On the other hand, without being part of the treatment team, the patient may not be aware that these periodontal issues may be connected to the diagnosis of PD. A multidisciplinary team approach that is centered around the patient and caregiver may lead to earlier detection of symptoms and ensure timely identification of relevant health issues that have the greatest priority in the eyes of the patient. Educated patients might even help in accelerating the diagnosis in early disease stages. For example, patients with repeated occurrences of a frozen shoulder that do not seem to fit the classical picture known to a physiotherapist or orthopedic surgeon, could be referred to a movement disorder specialist. Furthermore, proper and timely treatment of some gastrointestinal issues are reliant upon the doctor's awareness of the patient's diagnosis of PD.

Therefore, participatory medicine, in which patients work together as partners together with healthcare professionals, is gaining momentum [8]. Participatory medicine can take on many roles and shapes, as was elegantly outlined in an editorial in the British Medical Journal [14]. For example, exploring the needs of people with PD helped to shape the contours of a so-called CQ index, a specific instrument designed to obtain a factual account of the patient's experiences with healthcare services [15]. Some initial work is beginning to suggest that self-tracking of symptoms by patients, for example by performing episodic assessments on a smartphone, may not only be a useful tool to measure outcomes in research [16], but also help to adjust treatments to the specific needs of an individual patient [17]. Another example is the role of well-informed patients in making shared decisions, together with the health professional [18]. Work outside the field of PD has shown that many patients are able to participate in even complex decisions, helping them to receive care tailored to their own specific needs, and in fact also to help contain costs [19]. Also, recent work has shown the value of using deep interviewing methods to arrive at the core wishes and needs of patients, as a basis for the necessary innovations in healthcare [20]. We have even argued that in this new world of participatory medicine, the name "patient" has become outdated, as it is derived from the Latin word "patientia" that signifies suffering or patience [21]. To ascertain that patients can actually make the most of participatory medicine, specific educational programs may have to be developed to train and support patients in assuming an active new role in healthcare [22]. Importantly, such self-management strategies should focus not only on patients, but also on the caregivers [23].

Having the patient and caregiver as part of the team can make healthcare professionals more aware of the many different symptoms associated with PD, which in turn can lead to additional research, a better understanding of the disease, detection at an earlier stage, and hopefully, new treatment options. Finally, with the knowledge gained by working with multiple healthcare providers, patients can become better self-advocates and actively participate in the care delivered by the multidisciplinary team. Healthcare professionals need to get together with their patients and discuss treatment options. So, have a cup of coffee together and save a seat at the table for us!

2.2 The specialist in vascular medicine

The specialist in vascular medicine is a specialist in internal medicine, with a further dedicated sub-specialization in vascular medicine, including disorders of blood pressure regulation, dyslipoproteinemia, venous thromboembolic diseases and vasculitis. Regarding the care for people with PD, the vascular medicine specialist is typically involved in case of severe orthostatic hypotension (OH). Autonomic dysfunction is common in PD due to prominent loss of neurons in brainstem autonomic nuclei. Postprandial hypotension often coexists in these patients [24]. These hemodynamic sequelae can be exaggerated by the use of dopamine-replacing drugs that also lower blood pressure [25]. The prevalence of neurogenic OH in PD that results from autonomic dysfunction is approximately 30% [26] and in most patients this is associated with supine hypertension. Importantly, the clinical significance of OH in people with PD is illustrated by the negative impact on quality of life [27] and the association with recurrent falls and cognitive impairment [24,28,29], which emphasizes the need for adequate treatment.

Therefore, the American Autonomic Society and the National Parkinson Foundation recently advocated routine screening for OH in all people with PD [30]. Clinicians should minimally ask patients about symptoms of orthostatic hypotension, as follows: “Do you experience symptoms when you stand up or within 3-5 minutes of upright standing and does this improve again when you sit or lay down?” [30]. OH is defined as sustained reduction in systolic blood pressure of >20 mmHg and/or diastolic blood pressure of >10 mmHg within 3 minutes of standing [30]. An increase in heart rate <15 bpm is suggestive of neurogenic OH. That routine screening for OH is not superfluous, is illustrated by the finding that among people with PD in a Dutch nursing home, the prevalence of OH was 51.6%. However, this was rarely noted in the medical records, nor was it treated [31].

The goal of treatment is to alleviate orthostatic symptoms, rather than normalizing standing blood pressure. Prevention of complications of OH should be prioritized over treatment of supine hypertension. OH is clearly associated with increased morbidity, whereas the potential adverse effect of supine hypertension in these patients is less well established. The first step in the management of people with PD with symptomatic OH is to consider lowering or stopping potential drugs that can exacerbate OH, such as antidepressants, diuretics, and alpha-1 adrenergic receptor antagonists [30], if possible. The second step is to advise non-pharmacological measures to improve orthostatic tolerance, including an increase in fluid intake (>2 L/day) and salt intake (>180 mmol/24h). In addition, compression stockings (thigh-high) and/or abdominal binders can be used to prevent venous blood pooling upon standing, although the evidence for a beneficial effect is scarce [30], while many patients find it cumbersome to apply the compression stockings. Elevating the cranial end of the bed by 15-25 cm will limit nocturnal supine hypertension and the accompanying nycturia, which can alleviate orthostatic intolerance in the morning [32]. Moreover, avoidance of prolonged bed rest and dehydration can be advised. Small frequent meals are useful in case of postprandial

hypotension. When orthostatic intolerance remains, several drugs can be prescribed to increase blood pressure. Until recently, fludrocortisone and the alpha-adrenergic receptor agonist midodrine were used primarily for this purpose, with only midodrine having received FDA approval for the treatment of OH. In 2014, droxidopa also received FDA approval. For a more detailed treatment approach, we refer to previous excellent reviews on this topic [30,33].

2.3 The gastroenterologist

A gastroenterologist should be involved in the multidisciplinary team of people with PD at an early stage. A gastroenterologist with expertise and training in neurogastroenterology and intestinal motility may be particularly useful, as would a gastroenterologist with expertise in nutrition and endoscopic skills to allow for placement and maintenance of percutaneous feeding tubes for continuous intestinal infusion of medications, for nutritional support, or both.

The non-motor effects of PD on the gastrointestinal tract (GI) were already described in James Parkinson's original description of the disease in 1817 [34]. PD produces a multitude of GI symptoms including dysphagia, nausea and vomiting, early satiety, weight loss, constipation and difficult defecating [35]. Indeed, gastrointestinal symptoms are common in PD, with constipation occurring in up to 66% of patients [36]. Less well known are the esophageal abnormalities, however, up to 95% of people with PD will have a minor disorder of peristalsis [37], which can have a profound impact on their quality of life. For example, dysphagia may lead to drooling, weight loss and potential aspiration. Nausea, vomiting and early satiety related to delayed gastric emptying may cause significant discomfort, inability to eat and dramatic weight loss. Therefore, early detection and treatment of these problems is essential.

All stages of swallowing may be affected in PD. Bradykinesia and tremor prevent bolus formation and reduce transfer time [38]. Cricopharyngeal dysfunction (failure of the upper esophageal sphincter to relax and open when a person swallows) may occur even before patients develop significant symptoms [39]. Esophageal motility disorders ranging from esophagogastric outflow obstruction, diffuse esophageal spasm, ineffective esophageal motility and fragmented peristalsis have been described in people with PD [40]. Gastroparesis can also lead to an inability to deliver medications to the small intestine for absorption and thus produce some of the (largely unpredictable) response fluctuations that develop with long-acting medications used to treat the disease [41]. Chronic constipation may even precede the development of motor dysfunction and may therefore be present prior to diagnosing PD [42]. In PD, constipation may be caused by slow colonic transit or outlet dysfunction related to pelvic floor dysenergia. Dysenergetic defecation occurs when there is failed relaxation (or paradoxical contraction) of the puborectalis muscle and external anal sphincter during defecation.

Management of oropharyngeal dysphagia may require dietary changes and coaching by a speech-language pathologist. For example, drinking thickened or carbonated liquids rather than thin, uncarbonated beverages may improve swallowing function [43]. Cricopharyngeal dysfunction can be effectively treated with injection of botulinum toxin or by surgical myotomy [44,45]. Botulinum toxin can also be used to produce relaxation of the lower esophageal sphincter in outflow obstruction and achalasia, however, there are few targeted therapies for other disorders of esophageal peristalsis [46]. Domperidone, a peripheral dopamine D2-receptor antagonist, is often effective in managing symptoms of gastroparesis

in people with PD, but must be carefully monitored using ECG due to risks of cardiac side effects (e.g. prolonged QT intervals) [47]. Other treatments for gastroparesis include motilin agonists, ghrelin agonists and 5HT₄ receptor agonists [48]. Fiber supplements and osmotic laxatives are effective early therapies for the treatment of slow transit constipation [49]. Lubiprostone, a chloride channel activator, has also shown benefit in patients with constipation related to PD [50]. Finally, dysenergetic defecation may respond to dopaminergic drugs, position changes during defecation and pelvic floor physiotherapy [51].

2.4 The pulmonologist/respiratory rehabilitation specialist

A respiratory rehabilitation specialist is essential in the multidisciplinary team of people with PD. In case of co-morbid pulmonary disease (i.e. in addition to primary PD), it may also be advantageous to involve a pulmonologist, as the pulmonologist may prescribe suitable medication for bronchodilatation. People with PD often develop respiratory infections and pneumonia is one of the major reasons for hospitalization and even the leading cause of mortality in PD. In one prospective study, the observed mortality related directly to pneumonia was as high as 64% [52].

However, respiratory problems can also arise as a complication of PD itself. People with PD tend to develop decreased chest wall compliance, resulting in a stiff chest wall and increased work of breathing, which results in a decreased tidal volume as well as reduced vital capacity [53,54,55]. This in turn imposes an increased load on the respiratory muscles. As a result, the respiratory muscle endurance capacity decreases and patients develop fatigue of these muscles [56,57,58]. These symptoms usually worsen with time. Respiratory muscle fatigue can be detected by several methods, such as detection of incoordination of breathing by changes on the EMG. Incoordination of muscle movement and the breathing pattern further stiffen the chest wall, which then leads to decreased general endurance capacity.

In patients with respiratory diseases, but also in healthy subjects and in neuromuscular disorders (including patients with amyotrophic lateral sclerosis), respiratory muscle training can improve respiratory strength and endurance [59,60,61,62]. Recent work in 10 persons with PD demonstrated that an individually tailored program of pulmonary rehabilitation, in terms of degree of difficulty, duration and type of respiratory muscle training, significantly improved vital capacity as well as respiratory endurance capacity [63]. Therefore, the treatment options are: (1) to increase respiratory muscle strength and endurance by specific respiratory muscle training, resulting in improved breathing as well as general function of the body; (2) exercises to improve flexibility of the lungs and chest wall, as well as compliance and coordination of breathing; and (3) to improve respiratory endurance capacity, for example using a resistive breathing program for both inspiratory and expiratory muscles, which has also been found to be successful in severe amyotrophic lateral sclerosis patients [64].

2.5 The neuro-ophthalmologist

Most of the ocular symptoms experienced by people with PD can be diagnosed and treated by an optometrist or ophthalmologist (e.g. dry eyes, blepharitis). Generally, there are few ocular disorders that the neurologist and generically trained ophthalmologist cannot manage without the assistance of a dedicated neuro-ophthalmologist. However, when symptoms remain unexplained or fail to respond to conventional treatments as expected, neuro-ophthalmic consultation can aid in localization, accurate diagnosis and provision of tailored treatments.

Ocular symptoms are extremely common in people with PD and can have a significant impact on everyday activities such as the ability to drive, read or walk [65]. While the specific presenting complaint may indicate the underlying problem (e.g. horizontal double vision at near due to convergence insufficiency), the visual complaints are usually of a non-specific nature. They may, for example, simply be described as blurry vision or difficulty reading [66]. Blinking normally redistributes the tear film, and because blink rate is reduced in people with PD, in combination with inadequate production of tears, ocular surface irritation and dry eyes often results. Ocular surface irritation is often seen in conjunction with inflammation of the eyelid margins (blepharitis). Inadequate convergence produces diplopia or binocular blurriness, often experienced while reading [67]. The cause of inadequate convergence in PD remains generally unclear. Furthermore, the retina contains a variety of neuronal cell types, some of which are dopaminergic. Lack of dopamine may therefore contribute to loss of visual acuity, decrement in contrast sensitivity, and impaired color vision. Hallucinations are usually associated with daytime somnolence/insomnia, cognitive dysfunction and a long disease duration of PD [68]. All PD medications can cause hallucinations, although the dopamine agonists tend to be the biggest culprits. ‘Passage’ hallucinations are the most common and usually consist of formed objects (e.g. insects or small animals) briefly moving across the visual periphery [68].

Adequate treatment is essential and this does not have to be complex. For dry eyes, artificial tears can be used regularly throughout the day. Although the overall quality of the evidence is low to support the use of over the counter artificial tears [69], they are generally recommended as first line therapy. In more advanced cases, prescription medications (e.g., cyclosporine) or punctal occlusion are options. There is also some evidence to suggest that blink rate can be improved with levodopa [70]. Also, levodopa may lead to some improvement in terms of visual acuity, although acuity, color and contrast deficits tend to be subtle to begin with [71]. For blepharitis, lid scrubs and/or hot compresses can be used. For convergence insufficiency, convergence exercises – either done at home or with a vision therapist – may be recommended. Prisms may also be prescribed, which are incorporated into reading spectacles only. However, strong evidence to support the utility of eye exercises and/or prism therapy is lacking. Hallucinations require a separate approach, and the key role for the neuro-ophthalmologist is to aid in the identification in case of unclear cases. When hallucinations are tolerated and insight is preserved, reassurance may be all that is needed. More often, offending medication(s) like dopamine agonists will need to be reduced or discontinued, which is generally enough to improve hallucinations, although a worsening of motor symptoms may occur. There are several pharmacotherapeutic options for hallucinations, but this is the primary responsibility of the neurologist or psychiatrist in the team.

2.6 The urologist

Most persons with PD manifest some form of urological problems. This is mainly caused by the fact that the lower urinary tract, by definition the bladder and the bladder outlet (consisting of the urethra and the urethral sphincter or closing mechanism) have two opposite functions. During the filling phase of the micturition cycle, the bladder is supposed to relax and the urethral sphincter mechanism should contract. On the other hand, during the voiding phase of the micturition cycle, the bladder should contract in order to empty the bladder, whereas the sphincter mechanism has to relax to guarantee smooth voiding. Because these two organs have opposite functions (with opposite working mechanisms during the two

periods of the micturition cycle), the innervation of the lower urinary tract is complicated, consisting of many neural centers that are easily disturbed.

The filling phase of the micturition cycle takes about 23 hours and 45 minutes per day. Therefore, the most bothersome symptoms for patients are related to filling disturbances. This is not only true for people with PD, but it is the case for all neurogenic and even non-neurogenic diseases [72]. Lower urinary tract symptoms (LUTS) are common among patients with PD. It is estimated that neurogenic LUTS occur in almost 60% of PD patients [73]. Nycturia is considered to be the most prevalent of urinary symptoms in PD (>60%) [74] and is particularly bothersome, as it disrupts night rest, and also because the nighttime journey to the toilet can be dangerous as patients are typically off at night. Also, many patients do not switch on lights, being afraid to arouse the bed partner, but this makes walking at night extra dangerous. The most bothersome storage symptom is urgency, followed by nycturia and urgency incontinence [75]. One third of people with PD also experience bothersome voiding symptoms [73].

Antimuscarinics are the mainstay of medical treatment for storage LUTS in people with PD, while sparse data exist on the use of alpha-blockers. Surgical treatment of bladder outlet obstruction is no longer a contraindication in PD patients, as long as multiple system atrophy is excluded. Minimally invasive treatments, such as bladder injections with botulinum toxin A, percutaneous tibial nerve stimulation and deep brain stimulation can be considered in case of refractory symptoms [76].

In addition to urological problems, many people with PD also experience sexual disorders. Sexual disorders are among the most widely neglected non-motor symptoms in PD. Studies have shown a high prevalence of decreased libido and orgasmic dysfunction in both men and women with PD, and erectile dysfunction in male subjects. Moreover, sexual disorders in PD also include the increasingly recognized hypersexuality induced by dopaminergic medication, in particular following treatment with dopamine agonists [77]. Hypersexuality is very vexing for patients who have a limited ability to perform. Adjustment of dopaminergic medication can be helpful, but we often refer many of our patients to a sex therapist who can offer counseling and address alternative approaches to intimacy [78].

2.7 The geriatrician/elderly care physician

In the clinical situation, PD care is mainly carried out by neurologists and geriatricians. In some countries, for example the United Kingdom, both specialties provide PD care, affording them the opportunity to achieve specialist expertise in caring for people in advanced disease stages with complex comorbidities. For example, in the Netherlands, and especially in the nursing home setting, elderly care physicians (ECPs) are employed [79]. ECPs are community care specialists who have received additional training in addressing the needs of elderly patients with complex comorbidities (see *Table 1* for an overview of professional activities of the ECP). Geriatricians and ECPs work in both community and secondary care settings, but always within a multidisciplinary team to provide comprehensive and coordinated care. They frequently see people with PD in their own homes in the palliative stage of the disease when patients are no longer able to travel to clinic.

The prevalence of PD increases with advancing age [80]. Older people are a heterogeneous group who range from being very fit and active to those who are particularly vulnerable due to frailty. Frailty emerges when multiple functional domains are affected, which causes a decline of reserve capacity and an increase in vulnerability for institutionalization and death

[81]. Whilst a precise definition of frailty remains elusive, it is broadly recognized to represent a state that confers increased vulnerability to a stressor [82]. In older patients, motor and non-motor features of PD need to be considered in parallel with the management of comorbid illness, taking into account a patient's psychosocial and functional capabilities within their living environment. For example, throughout the disease, dopaminergic therapy should be finely adjusted in light of emergent neuropsychiatric symptoms, falls and hypotension and balanced against the requirement for other drugs such as antihypertensives.

The complex interplay of physical and psychological symptoms arising from PD, the burden of comorbid conditions and the vulnerability conferred by frailty, leads to poor quality of life and progressive loss of functional ability. This may include difficulties with managing complex medication regimes, increased dependence in activities of daily living, increased risk of falling and high prevalence of incontinence [83]. The presence of cognitive impairment and hallucinations with advanced age are potent contributors to the risk of admission to a nursing home [84,85]. Frail patients are frequently dependent on nursing homes, which may include services like geriatric rehabilitation centers, respite care and long-term care. Importantly, the toll of caring for someone with the condition is considerable, with increased anxiety, strain and social isolation resulting from diminished contact with friends and family [86,87].

Comprehensive Geriatric Assessment (CGA) is a holistic, multidimensional, interdisciplinary assessment of an individual by a number of specialists in a multidisciplinary team [88]. Interventions can then be tailored to the needs of the individual and their caregivers, and delivered by professionals with different expertise working within a multidisciplinary team. Drug wise, ageing is associated with altered drug metabolism, increased susceptibility to side effects and polypharmacy. The anticholinergic burden of some drugs used in PD (e.g. trihexphenidyl) and medications for other common illnesses (e.g. benzodiazepines, warfarin, furosemide) should be carefully considered given the cognitive vulnerability associated with PD [89,90].

In Europe, ECPs work across three main domains: (1) geriatric rehabilitation (which aims at functional recovery, using a problem-oriented multidisciplinary treatment plan [91]); (2) proactive consultation for community-dwelling patients (which consists of advanced care planning, case management, medication review and multidisciplinary ambulatory rehabilitation [81], and aims to postpone nursing home admittance and decrease the risk of hospitalization); and (3) long-term care, where ECPs are responsible for the general care. General care in long-term facilities often requires a unique skill set, as communication with patients can become difficult (due to speech and cognitive problems), the disease burden increases, psychosocial problems can arise and the nursing home environment can be challenging (due to staffing issues) [79,83,92]. The beneficial effect of involving the ECP is supported by the finding of a low (re)admission rate to hospitals of nursing home residents with dementia in the Netherlands, compared to other countries [93].

Recent small studies showed a very complex and high unmet care need in late-stage PD [94,95]. Moreover, a qualitative study suggested a lack of PD-specific expertise in nursing homes [95]. However, a treatment strategy for the complex issues mentioned previously does not readily fit into a standard management protocol and therefore effective care requires an integrated, bespoke approach. With their highly specialized skill set, geriatricians and ECPs, working within a multidisciplinary team, are well placed to help deliver holistic care to improve and maintain independence and quality of life throughout the whole disease course.

Further research is needed to fully determine the most cost-effective organization of long-term PD-care.

1.	Carrying out Comprehensive Geriatric Assessment
2.	Drawing up and implementing a holistic treatment plan
3.	Practicing emergency elderly medicine
4.	Advanced care planning
5.	Evaluating the ability to give consent
6.	Dealing with and limiting compulsory treatment
7.	Communicating with patients and the support system
8.	Collaborating with other care professionals (including PD nurse specialist and
9.	neurologist)
10.	Leading and collaborating with a multidisciplinary team
11.	Working with health care management
12.	Participating in integrative care
13.	Participating in quality monitoring of care and treatment
14.	Contributing to future development of elderly care and elderly care medicine
	Functioning as an ambassador for elderly in society

Table 1. Professional Activities of the elderly care physician [93].

2.8 The palliative care specialist

Palliative care for people with advanced PD seems to be a logical approach, as adding a palliative care specialist to a multidisciplinary team could help to improve the provision of basic palliative care interventions through all team members. However, there is presently little knowledge about how effective and useful palliative care for people with PD should be organized and whether this leads to better outcomes for patients [96].

As PD progresses, patients may experience a wide range of symptoms in the physical, psychological, social and spiritual domain that are potentially amenable to a palliative care intervention, such as pain or dementia [97-99]. As measured by *the Palliative Outcome Scale*, people with PD generally experience moderate palliative care needs [100]. Items most frequently rated as ‘severe’ or ‘overwhelming’ included walking difficulties, pain, problems using the arms and hands, difficulties in communication, fatigue, drooling, constipation, sleep disturbances and falls (101). Family caregivers (especially close family relatives) frequently have a crucial role in the provision of (palliative) care for people with PD. These caregivers report considerable changes in their lives because of the need to care for their relative [102-105]. They feel that their primary role in the relationship has changed. Consequently, caregiver burden continues to increase with disease progression over time, not rarely taking unacceptable forms. Indeed, one survey showed that many caregivers are on the brink of collapse themselves [106]. Obviously, this should be avoided at all cost, because loss of caregiver support will frequently necessitate an admission to more expensive inpatient care (not to mention the psychosocial issue of having to leave one’s own house).

Most family caregivers work incredibly hard to avoid an admission to a nursing home. However, eventually 20% to 40% of people with PD will be admitted to an elderly care facility [107-110]. In palliative care it is crucial to clarify the values, wishes and goals of patients and their spouses. A particular challenge here is that people with advanced PD may

lose their capacity to make decisions due to cognitive deficits, dementia or communication difficulties. Therefore, advanced care planning and discussions regarding end-of-life issues should be started timely.

Recent studies report the professionals' experiences with (the concept of) palliative care in PD [111-114]. Waldron et al. showed that professionals often misconceive the value of rehabilitation in the palliative care phase [112]. Moreover, professionals were shown to feel insecure about the care they delivered in the palliative phase because of a lack of education and competence in this field. Therefore, education in palliative care for all team members is necessary and could be provided by the palliative care specialist. Furthermore, a palliative care specialist can contribute to complex symptom control and quality of life of people with advanced PD. In *Table 2* we show a variety of clinical situations in which referral to a palliative care specialist can be considered. Further improvements in palliative care for people with PD, including evidence regarding PD specific interventions, is needed and should be based on the needs of patients and their spouses in order to develop potentially helpful strategies.

1.	End-of-life care
2.	Difficulties with controlling physical symptoms (e.g. pain, dyspnea, dysphagia)
3.	Feeding tube discussions or other complex interventions
4.	Serious comorbidities
5.	Rapid decline in function
6.	Restricted activities of daily living
7.	Multiple hospitalizations
8.	Spiritual concerns
9.	Distressing psychological issues
10.	Request for hastened death
11.	Home safety issues
12.	Communication issues within a family
13.	Need for capacity assessment or power of attorney disputes

Table 2. Referral to a palliative care specialist can be considered in the following situations [138].

2.9 The dentist

A dentist should be included in the multidisciplinary team of people with PD, in order to identify and treat PD-related oral conditions that can affect the overall health of the patient. In the field of dentistry, the most common problem found in people with PD is xerostomia (lack of saliva), commonly referred to as dry mouth [115,116]. Furthermore, in a study published in 2012 [117], researchers examined 90 people with PD and found that they had an average of four additional missing teeth per person compared to their age-matched peers without PD. Additionally, people with PD had significantly higher rates of periodontal diseases of increased severity compared to those without PD. The impact this has on a person with PD can be significant. Missing teeth affects the ability to chew food properly. This can further aggravate any swallowing problems already caused by the disease itself if food is not ground up sufficiently.

Saliva is particularly important, as it lubricates the oral tissues, assists in chewing and

swallowing, provides immunity to infection and it buffers, thereby preventing demineralization. Without saliva present, and consequently a dry mouth, the teeth are susceptible to decay. There are many factors that contribute to a dry mouth, such as open mouth breathing or salivary gland dysfunction, but it may also be related to PD itself, or be a side effect of the drugs used to treat the disease (for example the anticholinergics that are sometimes used to treat tremor). Furthermore, patients may avoid foods that are difficult to chew, such as meat or raw vegetables and instead rely on softer foods, such as puddings, cakes and ice cream. However, these foods are high in sugars and fats and lack fiber, and it may also lead to nutritional deficiencies.

There are multiple treatment options. A dry mouth can be lubricated with over-the-counter artificial saliva substitutes. Saliva production can be stimulated with the use of sugarless hard candy, citrus flavors being most effective, but overuse should be avoided as it can lead to gastro-intestinal upset. The consumption of sugar should be limited [118]. Sugar is metabolized by the oral bacteria, producing acid, which causes demineralization of tooth enamel, resulting in dental decay. Sugar-sweetened beverages should also be avoided, as well as irritating products such as alcohol, tobacco, spicy and acidic foods, and mouthwashes containing alcohol. Maintaining good oral hygiene by using adaptive adjuncts such as electric toothbrushes and floss aids is recommended. The mouth should be rinsed with water after every meal. For patients with oral symptoms or problems, a referral to their dentist about the use of fluoride, either an over-the-counter rinse or a prescription gel to strengthen the enamel, is advised.

2.10 The new role of the movement disorders specialist via tele-neurology

For patients with chronic neurological disorders, a medical specialist can improve quality of life and health outcomes. For example, among people with PD, those who see a movement disorder specialist live longer [119], receive higher-quality care [120], and maintain a better standard of living [120] than those who merely see a primary care physician or a general neurologist.

Historically, access to specialized care for neurological conditions was limited by distance and disability. With the increased proliferation, capabilities and acceptance of the Internet and mobile devices, specialists can now deliver care at a scale that was previously impossible (*figure 2*). This increased geographical reach has been clearly demonstrated by the growth of “tele-stroke” [121], that facilitates remote, virtual and rapid acute stroke expertise for local hospitals. Tele-stroke has become increasingly mobile, e.g. with mobile stroke units [122], and has improved access to stroke neurologists for millions [123-125].

For chronic conditions like PD, tele-neurology – the use of video conferencing to connect with patients directly in their own homes – has made significant gains in the last decade, with randomized controlled trials [126] and clinical care programs [127,128] in widespread national and international use. Tele-neurology reduces travel- and wait times for patients and clinicians [129], decreases cost burden on both health systems and those for whom they care [130], and allows specialists to reach patients who otherwise would be unable to travel to clinic. Some barriers remain, principally in the field of health insurance reimbursement [131] and licensure requirements [132,133], but successful models do exist [128,134], and much of the economic benefit accrues to patients [130].

The number of patients that specialists can see via tele-neurology is still limited by the specialists’ capacity, but other initiatives may be even more scalable. For example,

ParkinsonTV [135], an educational web-based television series coming from an integrated PD care program in the Netherlands called ParkinsonNet [136], has a widespread following and is now gaining traction in the US, where the first English language season has reached 250.000 unique individuals. ParkinsonTV and other educational series like this are products of the increasing trend towards “on-demand” education and care, in which individuals can access reputable and useful information about their condition wherever they are, wherever they live, and whenever they need it.

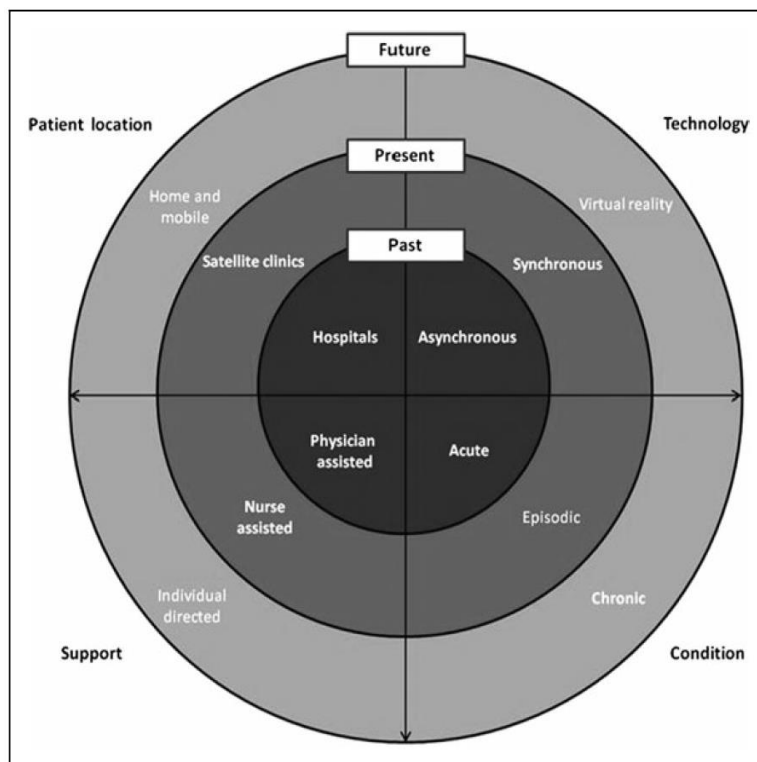


Figure 2. Expanding model of telemedicine care. *From Dorsey et al, Telemedicine and e-Health, Mary Ann Liebert, Inc. (with permission from the copyright holder) [139].*

3. Expert commentary

Here, we presented a selection of relatively new members of the multidisciplinary team that can potentially be involved in the treatment of people with PD. Importantly, this paper does not offer an exhaustive overview, and not all relatively newly recognized disciplines have been included here. However, the problems and symptoms described by each specific discipline will hopefully increase awareness about the complexity of non-motor symptoms that people with PD may experience, and therefore warrant early involvement of these disciplines, and lead to initiation of more efficient referrals to the appropriate healthcare professionals. This is of great importance, as one of the strongest arguments in support of multidisciplinary care is that communication between disciplines has a synergistic positive effect on outcomes [137]. A multidisciplinary meeting between all healthcare professionals represents the gold standard of holistic, patient-centered care and establishes a network of individuals with relevant expertise. Furthermore, the presented patient perspective perfectly

illustrates why it is of extreme importance to involve the patient and caregiver in the multidisciplinary team, in terms of promoting self-management, as well as providing connection between different healthcare professionals.

Importantly, the primary care physician has been all but forgotten in this paper. We have not included the primary care physicians here in the specialized, ‘traditional multidisciplinary team’ itself, because of their generalist role in healthcare practice. However, the primary care physician does have an essential role in the community, including making timely referrals to medical specialists, in handling co-morbidity, in implementing treatments in the patient’s own home environment, in helping patients to set priorities and in the palliative stage. A key challenge in healthcare is to now develop models where the indispensable generalist expertise of the primary care physician can be coupled seamlessly to networks of specialists in the field of PD.

We anticipate that tele-neurology, as described in paragraph 2.8, will play a vital role in increasing the availability of multidisciplinary care for many patients around the world in the not so distant future. In all probability this will not only involve remote care provided by the neurologist, but also care provided by a complete remote care team, including other healthcare professionals such as PD nurses, physiotherapists or speech-language pathologists. An even more provocative view of the multidisciplinary team could be that, in addition to the health professionals mentioned here, the team could also include a range of non-clinicians, such as health coaches, educators, (peer) support groups, sport coaches and financial advisors.

Optimal functioning of the multidisciplinary team is likely to improve markedly when a personal case manager is added to the team, especially for patients with cognitive problems or a complexly organized care system where patients may easily lose control over their disease. Unpublished work in the Netherlands shows that having access to a personal case manager who can act as a single point of access, regardless of the nature of the problem, is among the top priorities of families with PD (Van Vlaanderen et al., submitted). Such a personal case manager can likely address many simple problems directly, including alleviating anxiety or directing patients in the direction of another professional within the team who is better equipped to address the problem at hand. Some of these disciplines can use direct in-person contact, but most of these services could be organized remotely (e.g. by telephone, video or online) and even asynchronous (using secured text messages), as opposed to current dominant synchronous communication where the clinician and patient are co-located in space and time.

Future directions should aim at developing an integrated multidisciplinary approach for people with PD that accommodates a seamless assessment and management of both motor and non-motor symptoms. This should involve appropriate healthcare professionals that are available depending on a patient’s specific needs at a specific time. It should be a system that is able to change and adapt to the constantly evolving healthcare needs of the individual patient. Promotion of self-management should be deeply implemented in such a system, as well as the evaluation of caregiver burden and the cost-effectiveness of the approach. Further work is now needed to evaluate the merits of an optimal way of implementing a multidisciplinary approach that includes all professional disciplines, including the “new kids” introduced here, and an analysis of its cost-effectiveness.

4. Five-year view

As shown here, with our increasing knowledge of the multitude of symptoms that people with PD can experience, the need for an integrated multidisciplinary approach is gaining momentum. Future directions should aim at developing an integrated multidisciplinary approach for people with PD that accommodates seamless assessment and management of both motor and non-motor symptoms. This should involve appropriate healthcare professionals that are available depending on a patient's specific needs at a specific time. It should be a system that is able to change and adapt to the constantly evolving healthcare needs of the individual patient. Promotion of self-management should be deeply implemented in such a system, as well as the evaluation of caregiver burden and the cost-effectiveness of the approach. Further work is now needed to evaluate the merits of an optimal way of implementing a multidisciplinary approach that includes all professional disciplines, including the “new kids” introduced here, and an analysis of its cost-effectiveness.

Key issues

- With our increasing knowledge on the complexity and heterogeneity of symptoms that people with PD can experience, the need for an integrated, patient-centered multidisciplinary approach is gaining momentum.
- Specific healthcare disciplines, such as the movement disorder neurologist, PD nurse specialist and the physiotherapist, are already considered essential members of the multidisciplinary team.
- In this scoping review we explore a selection of relatively newly recognized, yet potentially important contributors to the multidisciplinary team of people with PD, including the specialist in vascular medicine, gastroenterologist, pulmonologist, neuro-ophthalmologist, geriatrician/elderly care physician, palliative care specialist and the dentist.
- Increased awareness about the range of non-motor symptoms that people with PD may experience and about potential roles of the ‘new’ healthcare professionals presented here will further improve disease management and quality of life of PD patients.
- Future directions should focus on developing an integrated multidisciplinary approach for people with PD and evaluate the optimal way of implementing this approach including all professional disciplines, also containing the ‘new ‘kids’ introduced here.

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Paragraph 2.8 “The palliative care specialist” is a contribution by Drs. Herma Lennaerts, Parkinson’s disease nurse specialist and junior investigator Palliative Care for people with Parkinson’s disease.

Paragraph 2.9 “The dentist” is a contribution by Dr. Jane Busch, former dentist and person with Parkinson’s disease.

Paragraph 2.10 “The new role of the movement disorders specialist via tele-neurology” is a contribution by Prof. Dr. Ray Dorsey, professor of Neurology specialized in movement disorders.

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Table 1. Professional Activities of the elderly care physician [93].

Table 2. Referral to a palliative care specialist can be considered in the following situations [138].

Figure 1. Example of the multidisciplinary team of a person with PD.

Figure 2. Expanding model of telemedicine care. From Dorsey et al, *Telemedicine and e-Health*, Mary Ann Liebert, Inc. (with permission from the copyright holder) [139].

